
Stem cell banking and the making of a patient "advocist"

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In 2005 Chris Hempel gave birth to twin daughters Cassi and Addi. In 2007, she and her husband learned that their girls had a rare, fatal disease called Neiman Pick Type C.

Four years later, Hempel describes herself as a "advocist" for rare diseases. She's an advocate for scientific research but also an activist seeking to bridge the gap between patients and researchers. One of her primary messages is this: If patients donate tissue (skin, in her case) that contribute to science, then they should get to know the results and participate in the research.

That sounds easy, but has proven difficult. She spoke to CIRM's Standards Working Group in April to discuss her experiences and encourage CIRM to take a leadership role in creating policies that engage and inform the tissue donors.

During her talk, she said, "If the entire goal is really to use a patient's own cells to cure them, well, you really can't cure a patient if they are just a number."

CIRM funds several awards that have the intention of creating reprogrammed stem cell lines from skin samples to better understand genetic diseases, much like the research Hempel participated in. These scientists have creating disease-in-a-dish models of schizophrenia, Parkinson's disease and autism using this approach.

One of the issues the working group discussed is the types of standards that should be in place to protect the rights of the people who donate tissues for these and other CIRM studies. In addition there was discussion about ways of providing information to potential donors, research participants and the public.

The agenda from that meeting contains additional information about tissue donation and iPS banking: [available here](#).

Here is Hempel's talk:

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Tags: iPS

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